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ABSTRACT

A study investigated the perceptions of Portuguese-speaking parents of children with disabilities concerning their involvement in their children's education. Specific aspects studied include their understanding of their involvement, nature and extent of current involvement, their ideals concerning involvement, and comparison with parents' involvement in the education of their children without disabilities. In addition, the experience of being the parent of a disabled child and the experience of being a bilingual parent in this context were also examined. Subjects were parents in nine families, and ethnographic interviews were conducted either in their homes or in a convenient location they suggested. Two major themes emerged in the parents' responses: (1) while children with disabilities must be educated to compensate for disabilities, what they can do is more important than what they can not do, and (2) the parents of such children should be viewed as rich resources, bringing a wealth of experience regarding their own culture and their child's abilities and learning styles, and often professional competence as well. Contains 23 references. (MSE)

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THE EXPERIENCES OF PORTUGUESE-SPEAKING FAMILIES WITH SPECIAL-NEEDS CHILDREN AS RELATED BY THE MOTHERS: AN ETHNOGRAPHIC INTERVIEW STUDY

Dr. Dora Tellier-Robinson

ED 431 321

The experiences of parents of children with special needs are usually more difficult, extensive, and complex than those of parents of non-handicapped children. The problems they face in other aspects of daily life are inevitably carried over into their involvement in their children's education. These problems can be further complicated if they are non-English-speaking, if English is a second language for them, or even, in some cases, solely by the fact that they are recognized as belonging to an ethnic minority. This qualitative study was designed to explore the attitudes toward parent involvement in their children's education by a number of Portuguese-speaking parents of children with special needs. Consistent with the nature of qualitative research, however, as data collection progressed the scope of the emergent findings widened to take in other aspects of these parents' experiences.

Statement of the Problem

The literature on parent involvement is quite extensive in general education, special education, and bilingual education. (Useful reviews of these studies are provided by Chavkin, 1993; Epstein, 1988; Graves & Gargiulo, 1993). There is also a growing body of literature that deals specifically with parent involvement in bilingual/special education settings (Baca & Cervantes, 1989; Harry, 1992b). Several studies are limited to documenting the attitudes toward parent involvement of various ethnic groups, primarily Hispanic (e.g. Harry, 1992a) and Asian (Matsuda, 1994; Yao, 1993), but only a few of these

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studies explore the parents' experiences with involvement or inquire into their needs and wishes. More particularly, no studies have been located on the involvement of parents of Portuguese-speaking bilingual/special education students.

The importance of a greater understanding of the Portuguese-speaking population becomes evident when it is noted that, according to the 1990 census, Portuguese is the tenth most widely spoken minority language in the United States. Between 1980 and 1990, the number of people in the United States born in countries where European languages other than Spanish are spoken declined by 13.8% During the same period, the number of people in this country born in Portugal and Brazil (countries where Portuguese is spoken) increased by 15.9%. This increase is due largely to greater numbers of Brazilians entering this country (Waggoner, 1993). Increasing immigration from Brazil should ensure that the numbers of Portuguese speakers in the United States will continue to increase. Margolis (1994) points out that even at the most conservative estimate, there is probably an undercount of the Brazilian population in the various regions of the United States ranging from 33% to over 80%.

Although much has been written about the importance of parent involvement, a focus on how parents want to be involved is a fairly recent development. Nieto (1992b) stresses this need, and a few researchers have investigated it (Dauber & Epstein, 1992; De Leon, Ortiz, Sena, & Medina, 1996). This emphasis on understanding the experiences and feelings of parents was the inspiration for the present study.

The Purpose of the Study

My purpose in this study was to seek to understand Portuguese-speaking parents' actual involvement and their feelings about their involvement in the education of their children with special needs. Exploring the experiences of these parents from their own perspectives may provide educators with new insights into parent involvement in bilingual/special education settings. It will also allow non-Portuguese-speaking educators to enter the world of Portuguese-speaking parents.

My overall research questions were: "How do Portuguese-speaking parents of special-needs children want to be involved in their children's education?" and "What are their expressed feelings about their involvement?" The following subquestions were addressed initially:

1. What is the understanding of these parents regarding their involvement in their children's education?

2. How are these parents already involved?

3. What would these parents consider to be an ideal parent involvement situation?

4. How does their involvement in their special-needs child's education compare with involvement in the education of their nonhandicapped children if they have them?

It is consistent with qualitative reseach methods that the focus of the study may be further shaped in process by the emergent findings (Ely, Anzul, Friedman, Garner, & Steinmetz, 1991). Because the following topics were continually introduced into the interviews by the participants, these two questions were added as foci for consideration as the study progressed:

5. What is the experience of being the parent of a handicapped child?

6. How do these participants describe their experience as bilingual parents of handicapped children in their relations with the school system?

Theoretical Framework

The theoretical perspectives within which the study was designed and conducted were derived primarily from the work of Nieto, Careaga, and Baca and Cervantes on parent involvlement. Nieto (1985, 1992a, 1992b) has consistently argued that schools need to change the way they look at parent involvement. She believes that in bilingual education parent-involvement programs may have actually discouraged parent participation. She suggests that the goal of parent involvement in bilingual education should be to educate and empower parents. Before parents can become involved, they must learn that they have the power to change the status quo. Ultimately, the schools must be "run by or with the community rather than for it" (1985, p. 187).

Perhaps the most comprehensive statement so far made of what parent involvement may mean for parents of limited English proficiency (LEP) was made by Careaga (1988) in a study in which he stated that "for many parents of limited English proficient students, however, involvement may be hindered by language barriers, limited schooling, different cultural norms, or a lack of information" (pp. 1-2). In his opinion, the challenge to bilingual education is to set up parent involvement programs that overcome these obstacles; before these programs can be developed, educators must find out the needs of the community, which is done by finding out about these parents' lives and looking at their interests and concerns. Once these factors are understood, Careaga argues, eductors would have taken the first step toward developing meaningful parent involvement programs.

Baca and Cervantes (1989), as a result of their work with LEP minority parents, emphasize the need to take into account the parents' language, culture, and attitudes towards handicaps when developing and implementing a parent-involvement program. Even though P.L. 94-142 (IDEA) mandates parent participation, there is evidence in the literature that participation by LEP parents of exceptional children is minimal. To the extent that this perception is generally accurate, lack of participation may be due to several factors. These include lack of knowledge by parents of their rights and conflicts between the attitudes and perceptions of professionals and those of the parents about a wide range of topics dealing with special education. In addition, professionals often perceive parental deference to them and preoccupation with such basic needs as feeding and clothing the child as apathy or lack of interest in education (Baca & Cervantes, 1989).

Method

The qualitative methods of ethnographic interviewing and participant observation were seen as particularly appropriate to the purpose of the study. Through these methods researchers seek to understand the experiences of other people and the meanings they make of their experiences (Ely et al., 1991; Seidman, 1991).

Selection of Setting and Participants

The focus in this study was on foreign-born LEP or bilingual Portuguese-speaking families who had at least one child enrolled in a special education program. I selected as a setting a nearby urban area with a large Portuguese population. This is a long-established

community where Portuguese speakers have been represented in the school system as students, teachers, and administrators for at least two generations. It also has a growing number of Brazilians.

I had already gained entry into the community through a pilot study. I had become acquainted with a Portuguese-speaking official at the central board of education who worked with bilingual programs. He gave me the names of special-education teachers and administrators whom he thought could help me as well as the name of a Portuguese friend with a special needs child. I also received a few names from a teacher. I contacted these potential participants; others were obtained through "snowballing" as one participant suggested another (Seidman, 1991, p. 45). Some potential participants did not meet my criteria; others were not able to arrange time for interviews. For those who were able participate and who met the criteria, permission forms were obtained and pseudonyms were assigned to protect confidentiality.

At least three interviews of at least 90 minutes each (Seidman, 1991) were held with each participant. Interviews were held in the participants' homes or, in the case of two participants, in another location they selected as more convenient. The participants were given the choice of speaking in either Portuguese or English. Seven of the nine families chose to speak in Portuguese. All interviews were taped, and the tapes were transcribed (and translated into English as needed). These transcripts then became part of my log. (See Appendix A for Interview Schedule, Appendix B for Interview Guide, and Appendix C for a sample of a translated interview)

In all cases I visited the participants' homes, met all members of the families, and spent time observing, talking with, and/or playing

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with, the special-needs children and their siblings as appropriate. Although I had not deliberately sought participants whose children's disabilities were of a serious nature, through the selection process described above this turned out to be the case. I therefore considered it important to observe the children in their natural family settings as a supplement to the interview data. Detailed notes compiled after each observation and interview session became part of the ongoing log. Concurrent analysis of the gradually accumulating log data was used to help shape future interviews.

New participants were added until I attained a saturation of categories (Seidman, 1991) for analysis (i.e., no additional data yielding new categories or thematic material were being documented). In all, I interviewed nine families for use in this study. All were two-parent families, and there were siblings in all but one of the families as well. The interview participants were the mothers of the families in eight of the nine families. In one family, both mother and father were present for all interviews.

Analysis of Data

All data collected in the log were analyzed inductively, moving from specific raw units of information, for which codes were established during initial analysis, to larger categories (Ely et al., 1991; Lincoln & Guba, 1985). The original categories were then reviewed, refined, and combined as necessary. A few examples of final categories include: family attitudes toward having a special-needs child, daily care requirements, parents' relations with school personnel, and opportunities for involvement in child's school.

After all categories were established and raw data grouped under category headings, I studied the data for thematic connections within and among them. Themes were defined as "a statement of meaning that (1) runs through all or most of the pertinent data, or (2) one in the minority that carries heavy emotional or factual impact" (Ely et al., 1991, p. 150). Following the steps outlined by Ely et al. (1991, pp. 150-152), a thematic analysis was undertaken of the final categories. Thematic statements were constructed that expressed the understandings and feelings of the participants, and the discussion of findings was organized according to these thematic elements.

Findings

The presentation of findings opens in Chapter IV with the "Family Portraits" of each of the nine families. The portraits were based on selections from interview data previously translated which were edited to eliminate repetition and shaped to provide chronological order to the accounts. The participants' own words were retained as much as possible to provide an opportunity for them to tell their own stories.

Analyzed data were grouped under two overarching categories: Chapter V is focused on the special-needs children and their families. Chapter VI deals with the families' experiences with their children's education. The findings are summarized and discussed at the close of each of these chapters in the form of thematic analysis.

The first theme in Chapter V--"The Families and Their Children with Special Needs"--states that "Having a handicapped child required tremendous adjustment for our family." Because the children's disabilities were of a serious nature, in many cases they were noticed

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at birth. In other cases, however, the parents detected "something wrong" and tried, sometimes with difficulty, to explain their concerns to health care professionals. These experiences are discussed under the theme "I could not make the doctors listen to me when I tried to tell them that there was something wrong with my baby."

The efforts of all members of the families to meet the special needs of these children, and the parents' attitudes toward this aspect of their lives, was of particular relevance to the focus of the study. The thematic statement that emerged was, "My special needs child requires a lot of extra help and attention." For example, one mother described how, beyond the care that most three-year-olds require, she had to take her daughter, who has cerebral palsy, to her physical therapists at least twice a week. She not only had to learn from these therapists how to work with the child at home, but also how to perform such "simple" tasks as holding, carrying, and bathing her.

As these children grow older, their needs may change, but they still usually require more care than other children. A father told me that he was the one who shaved his 15-year-old son with Down syndrome, and how he had to take him to school because he had refused to ride the school bus. This father also reported that he took his son "everywhere" with him, not only to expose him to a variety of experiences, but also for him to walk for exercise. In all cases, much time was devoted by family members, including siblings, to the physical care of the child and to whatever therapies were dictated by the nature of the child's disability. Meeting these daily needs, and helping the children to become independent to the extent possible, were seen by the parents as a large part of each child's educational program.

A particularly relevant topic is language use within the families. The table in Appendix D shows the length of residence in the United States of each of the participants, records the language used for the interviews, and indicates my assessment of the language fluency of each participant. An unanticipated finding was expressed by the theme, "The learning problems of these children have not prevented them from learning a second language." I documented that to the extent that each special-needs child was able to speak at all, he or she appeared to be equally fluent in both English and Portuguese.

It is interesting to note here that in some of these families the children who seemed to be most proficient in speaking both languages and who had the greatest interest in the Portuguese language and culture were the children with special needs. One of the mothers remarked that her non-handicapped children understood Portuguese but did not speak it because they preferred to speak in English. It seemed to me that this interest on the part of the special-needs child might be due to the close ties that some researchers have noted between mothers and their special-needs children (Hardman, Drew, Egan, & Wolf, 1993). The parents reported that they took these children with them "everywhere," while their nonhandicapped children might be more involved in their peer culture. The three-year-old girl with cerebral palsy could already speak both Portuguese and English and knew that she spoke Portuguese at home and English at school. At the same time, her nonhandicapped siblings were just starting to learn English.

The final theme in this chapter--"This child has been a gift from God"--synthesizes statements made by many of the parents when discussing their feelings about their experiences as the parents of special-needs

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children. When talking about what these chldren meant to them and their families, they indicated that they saw them as "a gift from God," and an inspiration to other members of the family. One mother conveyed her deep feelings this way:

> Nelson didn't die because I believed that God didn't want him to die. . . .God wanted me to take care of Nelson. He knew how much we loved Nelson. He is my angel.

Another mother said that her daughter Dolores was a blessing and that God had given Dolores to her because He knew she was the right person to take care of a handicapped child. Some of the families also expressed ambivalence, however, or a note of bitterness or resentment as much for their children's being robbed of a more normal childhood as for their own difficulties. Most of these parents seemed to experience a combination of these attitudes.

There appears to be an emphasis in the literature on the stress to a family caused by a child's disabilities to the exclusion of other, more positive, aspects of the experience. One exception, however, is found in the work of Correa (1989), who pointed out that professionals need to take into account cultural beliefs when intervening with parents of diverse backgrounds. Although none of the participants in this study discussed the specifics of religious belief that might support their attitudes, the findings seemed to be analogous to those of Baca and Cervantes (1989), who cite earlier studies that indicate there is a positive correlation between religious belief and maternal acceptance of handicapped children and that Catholic families appear to be more accepting than others.

The focus in Chapter VI is on "The Families and the Children's Education." The first topic addressed is the experiences of these

Portuguese-speaking parents in an urban school district. Most of the children in the study were born here, but three of the families came to the United States especially because they perceived that the educational system here would offer advantages not available to them in Portugal. Although they reported that they did indeed find the eductional opportunities they were looking for, it was also their impression that in Portugal the services would have come to them automatically whereas here they had to learn how to be advocates for their children and to cope with "the system."

Issues around the experiences of these LEP parents in an urban school district were discussed under the theme: "We have to ask for what we want and fight for our children. Lacking proficience in English makes it more difficult for us to understand the school system and learn how to procure the services to which our children are entitled." Three participants specifically addressed language and ethnicity as barriers to obtaining services for their special-needs children. One mother, whose daughter has spina bifida, believed that there was a general lack of interest in the Portuguese community on the part of the board of education and a lack of cooperation between the board and the community:

> The Portuguese people are not well represented here. We need an advocate for us because the parents complain and the board doesn't do anything. The Portuguese parents have to learn to be advocates for themselves, too, so that they can help each other.

The father whose son has Down syndrome reported that when he went on one occasion to the administrative offices in his district, "There wasn't anyone there who speaks Portuguese and who could help us."

The second theme stated: "Involvement in the education of my child with special needs consumes far more time than involvement in the

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education of my other children." The participants discussed parental involvement in both the home and the school. It was clear that they considered their involvement at home in the care and therapies needed by the special-needs child and the outings on which they took them as an important aspect of the child's education. They also pointed out that these children's schools had more meetings and that there were more parent conferences than in the schools of their non-handicapped children.

When discussing their attitudes toward parent involvement, almost all of these participants mentioned that they liked to be involved and wanted to be involved in their children's eduction. One mother stated:

> It is very important to be involved in your child's education, especially when you have a handicapped child. If we are not involved, they won't do anything. They will be passive and uninterested in the world and people around them. If all children, including handicapped childlren, had the support of both parents, they would do much better and they would achieve more. We as parents must be involved in all phases of our children's lives, whether they are handicapped or not.

Several of the participants expressed the view that by being involved in their children's education they were able to be better informed about what was being done for their children. As one mother said: "By participating in Quim's education, I found that I learned to understand what he was learning and why he was learning it." However, although all the participants stated that involvement in the school is important, almost all of them expressed the opinion that the most important involvement takes place at home.

These participants also expressed strong concerns for their children's future. Those with older children were concerned that the schooling available for these children was aimed at keeping them occupied and helping them live independent lives, but that it did not

always challenge their abilities or meet their special interests. It was clear that they saw involvement in the child's education as a lifelong commitment. One mother expressed this common sentiment as "always being available for my child and involved in everything she is doing." Another highlighted the mutual aspects of the relationships: "I'm not only involved with my daughter, but she is also involved with me and my life. We care about each other. I help her and she helps me."

Finally, analyzing comments about parent involvement programs in the schools, the theme emerged that "The schools do a lot to support and involve parents of special-needs children, but we have ideas about how they could do even better." Among the suggestions were that transportation be provided for parents who do not drive and that more activities be held during evening and weekend hours to accommodate working parents. One of the mothers, herself a teacher, touched on several points mentioned by other parents when she said:

> Another thing would be to have more things locally for parents so that they are able to attend conferences and attend meetings in different neighborhoods. . . . We could have a speaker in the parents' native language. We don't have that, so a lot of the Portuguese parents don't go anywhere. . . . Also, we should have more professionals who are bilingual.

Conclusions and Implications

The conclusions and implications for practice derived from this study are discussed under two overarching metathemes that ran throughout the data. The first is: "What these children can do is immensely more important than what they cannot do." As has been noted, the parents of older children felt that the children could be further challenged and their special talents and skills emphasized. Although it is essential that these children be educated to compensate for their disabilities, it

seems necessary also to deemphasize the deficit model and raise expectations for the children. The ability of many of these children to speak two languages seems of particular interest, and further research in this area seems indicated.

The second metatheme is: "Parents of such children need to be viewed as very rich resources." *The participants in this study brought* a wealth of experience regarding their own culture, their child's abilities and learning style, and often had professional competence to contribute as well. They spoke of their potential contributions to educators and to other parents being ignored, and some indicated that they felt that they were in an adversarial relation with "the system."

There appears to be a widely-held belief among teachers that many parents, especially minorities, immigrants, and those of low socio-economic status, are not interested in participing in their chidren's education (Chavkin, 1989). However, studies exist that indicate that these parents are interested in and want to be actively involved in their children's education (Chavkin, 1989; Williams, 1991). The present study supports such prior research and presents a group of parents who are not only already highly involved but also have suggestions for further and more effective involvement.

Ideas for developing programs for parent involvement should not only be initiated by schools but also solicited from parents. Parents need to feel that what they say is valuable and taken into consideration. Beyond this, parents need to see some of their suggestions put into practice and to help assess these as part of a profesional dialogue. This study bears out Nieto's (1992b) contention that we need to ask parent what they want and listen well to the answers.

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